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SUBJECT: FR Docket # 04-7984 - **Notice of Proposed Revisions to the Mandatory Guidelines for Federal Workplace Drug Testing Programs**

Dear Dr. Vogl:

Thank you for offering the FR Docket # 04-7984 Proposed Revisions to the Drug Testing Guidelines to the American Public for comment.

My name is Phil Baumgaertner, and I'm a licensed Mechanical Engineer, BSME. I retired last year after a 33 year career as a civilian engineering manager at one of the Navy's public owned Shipyards.

I never used illegal drugs and never knowingly hired anyone that did. However, in the 1980's when the Navy discussed the implementation of civilian drug testing, I had a feeling of dread because I knew that my career could be over at any time I was tapped for a random drug test. My secret was that I had shy bladder disorder since the age of 10, and would not have been able to provide a urine sample for a drug test. (Paruresis, or what is commonly labeled shy bladder disorder is categorized as a social phobia disorder by the psychiatric manual DSM-IV)

I sought help for the disorder from family doctors, eventually 4 urologists, a psychiatrist, a hypnotist, a biofeedback therapist, and yet none of these professionals were able to help or even put a name to my problem. In 1997, I did a search of the internet and met the individuals from Texas and Maryland that eventually founded the non-profit International Paruresis Association (IPA). It was an "electronic" coming together of shy bladder patients, who generally were not being adequately treated by psychologists or medical doctors. Since that time, I've read thousands of posts from people suffering from shy-bladder, gone to 3 three-day IPA workshops, participated in a Seattle support group, read 40 to 50 books on anxiety and phobia treatment,

2 urology books, and most recently, a relevant book about brain neuro-science by Rush Dozier, called "Fear Itself". I've been a discussion moderator for IPA for 6 years and recently a member of their Board of Directors. (I've gone through this to let you know my knowledge in this area and certainly that of my IPA colleagues very likely exceeds that of most MRO's)

Dr. Joseph A. Thomasino, an MRO, provided Public Comment 8400013 and also kindly sent a clarifying letter to IPA staff to disburse to our membership. I'll provide a partial quote below because I think the opinions expressed therein are relevant to common attitudes encountered by shy-bladder donors:

> "I have been acting as a Medical Review Officer (MRO) for more than 14 years, the last 10 of which I have been exclusively engaged in MRO practice. In that time I can recall reviewing more than 60 shy bladder evaluations (i.e., examinations of urine drug test donors who were unable to provide sufficient urine). Of these I can recall that two of these evaluations involved donors that could provide medical documentation that they were diagnosed with Paruresis prior to the test and for these donors the tests were simply cancelled with no sanction of any kind applied. However, the vast majority of these 60 or more cases could produce neither medical documentation of a pre-existing psychological disorder like Paruresis or evidence on examination or history of an ascertainable physiological condition (e.g., a urinary system dysfunction) that did or reasonably could have precluded the donor from providing sufficient urine in the time frame allowed. Many of these, on examination, offered dehydration or "situational anxiety" (not Paruresis, usually something akin to "white coat syndrome", i.e., that they usually can and do urinate in unfamiliar surroundings or public facilities at workplaces, restaurants, theatres, stores, etc., but can't urinate when a health care professional or supervisor demands it of them). For these, serious sanctions were applied often including dismissal from their jobs or not being hired in the first place, because they were considered to have refused to provide an adequate specimen for testing in accordance with 49 CFR Part 40.193."

Dr. Thomasino's criteria for a legitimate shy bladder donor appears to have 3 attributes:

1 The donor must have advance documentation of a psychological disorder like Paruresis, or

2. Evidence on examination or history of an ascertainable physiological condition,

and

3. Situational anxiety is not paruresis (49 CFR Part 40.193)

These criteria are flawed for reasons to be discussed below:

Criteria #1 - Advance Documentation of a psychological disorder

> The majority of the new posters to our IPA Discussion Site do not have any documentation of their condition. Many of the employment complaints we receive are by folks that would tell you something like what I heard in an investigation two months ago: "I don't have a psychological problem; I just can't pee when I've got 2 female collectors standing 4 feet outside the stall door in the men's restroom wanting me to get on with it." Like me, many folks with this disorder have found ways to work around it and they don't consider themselves as needing psychological help. Any testing protocol that requires advance documentation is flawed since many medical conditions, e.g. diabetes, cancer, MS, etc. are often not diagnosed in a timely manner. The incidence of delayed diagnosis should not be grounds to deprive one of employment or of a job offer.

Criteria #2 - Evidence on examination or history of an ascertainable physiological condition

> One research paper on shy-bladder-like disorders concluded that the contribution of physiological causes to shy-bladder was negligible. From a purely anecdotal standpoint, IPA moderators encountered relatively few posts from patients whose doctors found something physiologically wrong with them. Yes, there has been a few urethral strictures found, in one case the shy-bladder diagnosis was changed by the doctor to multiple sclerosis, but in general, there has been no physical marker that urologists can find from urethral inspections or other available diagnostic tools. The concept that enlarged prostates are responsible for shy bladder is not valid since a Canadian study showed that just as many women develop this disorder as men.

Criteria #3 - Situational Anxiety is not Paruresis.

> Of course it is. I've read thousands of posts on our website from those with paruresis, ranging from severe cases where people can't urinate anywhere but their home, to mild cases where they can use stalls but not urinals. Every one of these folks can recite in detail which situations will cause problems for their urination system, and which will not be a problem. The following may be problems for some with paruresis but not others: airplane lavatories due to motion, noise, and lines, hospital overnight stays, fan noise in public restrooms or lack thereof, close proximity of strangers or friends in public restrooms, the restroom size affects some - many are more comfortable in larger versus smaller restrooms, how busy a restroom is, the degree of privacy offered by partitions, if they exist, etc. A recent popular book estimates that 1 in 8 people will suffer a phobia sometime in their life, with social phobias being more difficult than single phobias to recover from.

Those of us with paruresis can know that many of our situational anxieties are irrational, but conscious knowledge does not equate to voluntary control of the urination reflex.

Its very disheartening to hear from Dr. Thomasino that he disallowed 58 out of 60 claims of shy bladder disorder and that "serious sanctions were applied often including dismissal from their jobs". For a human to urinate, the inner spincter must relax and the detrusor muscle must simultaneously contract. Both of these actions are controlled by the autonomic nervous system and are involuntary in nature. The exterior spincter is the only urination system component under voluntary control. How did the United States Government decide to take punitive action against those individuals whose involuntary urination system is not responding properly? Are we also going to punish those individuals who have OCD, Parkinson's, MS, cancer, or the common cold? Previous policies on how to deal with urination problems discovered by drug testing procedures do not appear to have been based on medical science or any of 60 plus research reports on paruresis related topics that have been published since 1922.

Two cases of shy bladder in the 14 years that Dr. Thomasino has been an MRO is a ridiculously low number. Even 60 claims seems too low for the number of shy-bladder donors out there. What MRO's are calling shy bladder because of an inability to provide a urine sample may also be due to other reasons. The book: "Conquering Bladder and Prostate Problems" by Jerry G. Blaivas, MD, Copyright 1998 by Plenum Press lists many reasons other than shy bladder for urination difficulties. These include medical conditions such as diabetes mellitus, MS, stroke, various prostate conditions for men, spinal cord injury, herniated disc, idiopathic bladder, vesical neck obstruction, etc. The question again arises, why is the United States Government terminating the employment of people who can't urinate due to diseases or disorders beyond their control?

If you're coming to the conclusion that sorting out urination difficulties is too difficult for a massive drug testing program, you are absolutely right. However, the increasing number of lawsuits which have found in favor of the shy-bladder donor this year (in March 2004, a jury awarded a medical doctor $256,000 for his shy-bladder termination by the Presbyterian Health Services Corp. of New Mexico) mandates that some action be taken to avoid future law suits resulting from lost employment of American citizens.

I recommend the following actions:

1. Reassign anyone who says they have shy bladder to oral, hair or sweat testing.
2. Reassign anyone having difficulty providing a urine sample to oral, hair, or sweat testing.
3. The proposed guidelines mention in Section 2.3 that "permission can be obtained from the Federal Agency to collect an alternative specimen" for shy bladder or insufficient specimen situations. This is too cumbersome for shy bladder which surveys show exists in 7% of men and women. No individual permission system is going to work for the actual number of shy bladder cases.
4. Section 2.3 suggests that a urine specimen to be collected any time a oral fluid

sample is taken is obviously not going to work for people with shy bladder. For one thing, they can't provide a urine sample and for a second reason, it makes oral fluid testing much too expensive since essentially two tests have to be accomplished vice one. I have reviewed the lab testing recently accomplished by Orasure and it shows that passive THC contamination of oral fluid from room smoke is not a problem if one hour has elapsed since the donor left a room contaminated by marijuana smoke. No second biologic sample is necessary.
In Section 2.1, the proposed change states: "The Department wants to make it very clear to agencies that there is no requirement that they use hair, saliva, or sweat as part of their drug testing program, but rather that agencies may use those specimens." This cannot stand because it directly results in continued employment discrimination against those of us with shy bladder disorder. Our current 800 shy bladder "contributing friends" of IPA deserve to apply for employment in the same way as any other American citizen. It cannot be optional for Agencies to decide whether to terminate employment as opposed to making alternative drug tests available to shy bladder donors. Agencies should not be discriminating against shy bladder donors anymore than they are allowed to discriminate against one's gender, one's race, etc. when considering employment applicants. We with shy bladder seek to participate in drug testing on an equal footing with everyone else. Somehow, shy bladder is equated with illegal drug usage via this loaded term: refusal to test. Inability to provide a urine sample has never been the same as refusal to test and courts seem quite able to understand the difference.

I once asked my urologist if he had any more shy bladder patients like me. He said yes, he had at least 6 or 7. I asked how he knew. He replied: "Well they don't talk about it like you do, but they can never provide urine samples when they come into my office" This doctor was right, those with this social phobia are typically reticent.

Shy bladder donors have long suffered from not having a voice in drug testing circles. I believe that the IPA organization has finally provided a willing voice for shy bladder testing complaints. With the advent of alternative testing that is being pioneered by SAMHSA, there is now not only the central voice but the methods to provide shy bladder donors equal access to employment. Being retired, I can readily offer my services free of charge to SAMHSA to consult on any shy bladder questions. Please don't hesitate to ask.

Respectfully,

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